

The Stigma of Lung Cancer

Joan H. Schiller, MD, Alice Goodman, MA

Jul 18, 2013

Are Lung Cancer Patients to Blame for Their Disease?

Editor's Note: *Because many people perceive lung cancer as self-induced -- the result of cigarette smoking -- there is a stigma associated with lung cancer that does not afflict patients with other cancers. At the 2013 Annual Meeting of the American Society of Clinical Oncology (ASCO®), Medscape spoke with lung cancer expert Joan H. Schiller, MD, University of Texas Southwestern Medical Center in Dallas, Texas, about her poster presentation^[1] on attitudes toward lung cancer vs breast cancer and the stigma associated with a lung cancer diagnosis.*

Medscape: What led you to conduct this study?



**Joan H. Schiller,
MD**

Dr. Schiller: Those of us who treat patients with lung cancer have observed that our patients suffer from guilt and stigma associated with their disease. Many people believe that -- unlike most other cancers -- lung cancer is self-induced. However, they do not take into account that most people started to smoke before they knew better. Most of the cancers associated with cigarette smoking occur in patients who started in the 1960s, before the research was done about the connection between cigarette smoking and lung cancer. The stigma associated with lung cancer is a real problem that is not associated with self-induced diseases, such as heart disease or diabetes.

Medscape: Because 90% of lung cancers are associated with smoking, I assume that is why people believe the cancer is self-induced.

Dr. Schiller: Quitting smoking is very difficult. Smoking cigarettes is as strong an addiction as heroin, and once you start, it is very difficult to stop. In fact, 75% of all smokers have tried to quit but have been unsuccessful. However, lung cancer can occur in people who have managed to quit as well. In fact, it is estimated that about one half of all lung cancers occur in former smokers.

Researchers have identified some genes that lead to nicotine addiction. People with these genes who start to smoke cigarettes become more addicted than those who lack those genes.

In thinking about how to combat the stigma associated with lung cancer, which we believe is unfair, my coauthors and I decided the first step was to quantify attitudes.

How Negative Are Public Attitudes?

Medscape: Tell me about the study details.

Dr. Schiller: This was an online study that involved over 1700 respondents from different sectors, including healthcare providers, public caregivers, and patients.

We wanted to study explicit or conscious attitudes and implicit or unconscious attitudes toward lung cancer. Explicit attitudes were captured by answers to specific questions, and implicit attitudes were captured by responses to a rapid series of photographs and words.

We needed a comparator so we could show that attitudes toward lung cancer were more negative than attitudes toward another type of cancer. We selected breast cancer as a comparator because we felt it was associated with little guilt and stigma and is not perceived as a self-induced disease. Also, breast cancer has a strong patient advocacy movement supporting public awareness, and to a great extent, this has overcome any stigma that may have been attached to it many years ago.

Medscape: How did you test for explicit attitudes?

Dr. Schiller: Participants were asked to agree/disagree with statements on a scale from 1-6. Statements could be: "Patients with lung cancer ought to be ashamed of their disease" and "Patients with breast cancer ought to be ashamed of their disease."

Medscape: And implicit attitudes?

Dr. Schiller: We used the Implicit Association Test, which has been used in the social sciences. Words are flashed on a computer monitor screen, and the participant is asked to associate them as positive or negative by pressing 1 of 2 keys on the keyboard. For example, the participant may be asked to press the letter "E" for a positive word, such as "hope," and the "I" key for a negative word, such as "shame." This all happens rapidly, and the reaction time is measured.

Participants were also shown a series of pictures or drawings about lung cancer or breast cancer, and then were asked to press "E" or "I" depending on whether the words "lung cancer" or "breast cancer" were on the right or left sides of the screen.

Medscape: What did you find?

Dr. Schiller: Participants were very accurate in making classifications, and the reaction times were typically under 1 second per item. However, they found the task easier and had faster reaction times when lung cancer and negative words were mapped to the same "E" key and breast cancer and positive words were mapped to the same "I" key. In contrast, they found the task more difficult and were slower to respond when lung cancer and positive words were mapped to the same key. The differences in reaction times across these conditions were significant, suggesting the presence of unconscious attitudes that associate lung cancer with negative attitudes relative to breast cancer.

The bottom line is that both the explicit and implicit tests revealed much more negative attitudes toward lung cancer than toward breast cancer. For explicit attitudes, about 70% of all participants had a negative attitude about lung cancer, compared with 8% about breast cancer; 22% of participants had neutral attitudes about both cancers.

For implicit attitudes, about 74% had negative attitudes toward lung cancer, 20% against breast cancer, and 16% were neutral. Surprisingly, negative attitudes did not differ among groups.

Destigmatizing Lung Cancer

Medscape: What is the next step?

Dr. Schiller: Once you measure something, you have a better chance of developing interventions for approaching the problem. Our next step is figuring out approaches, but it will be easier to engage people in that effort now that we have such striking numbers.

We were surprised that healthcare providers had negative biases consistent with other groups. We are now specifically recruiting physicians to participate in the research to better understand whether there is variation among different types of physicians -- general practitioners, pulmonologists, thoracic surgeons, and oncologists.

We encourage your readers to take the test at www.thelungcancerproject.org.

Women with lung cancer have told people they have breast cancer, because they are ashamed

Medscape: Do you see changing trends in the types of patients who are diagnosed with lung cancer?

Dr. Schiller: Yes. For several years, we have seen a growing population of young women who are never-smokers being diagnosed with lung cancer. These patients tend to have *EGFR* mutations and *ALK* rearrangements.

This fits in with the stigma story, because these young women are tainted by the stigma and guilt associated with lung cancer in that they have no strong advocacy group fighting on their behalf. If a young woman with breast cancer is sitting next to a young woman with lung cancer in an oncology clinic, the breast cancer patient has a wealth of resources, whereas the lung cancer patient does not.

Medscape: The breast cancer patient advocacy movement has done a good job of educating the public and destigmatizing a diagnosis of breast cancer.

Dr. Schiller: Yes, women with lung cancer have told people they have breast cancer, because they are ashamed of the lung cancer diagnosis. Part of the reason for the success of the breast cancer advocacy movement is that there are so many survivors of breast cancer, whereas few people survive lung cancer.

Never-Smokers: A Growing Trend

Medscape: How do explain this trend in young female never-smokers?

Dr. Schiller: The short answer is that we don't know why lung cancer is on the rise in young women who are never-smokers. There are so few data. We are seeing larger numbers of younger women who are never-smokers diagnosed with lung cancer. Nobody knows why.

One hypothesis is that it is somehow related to estrogen. Preclinical studies suggest that there is a 2-way relationship between estrogen and the epidermal growth factor receptor pathway. The suggestion

came from population studies that looked at hormone replacement therapy (HRT) retrospectively and showed that lung cancer patients on HRT had a poorer prognosis than those who never took it.

Other pieces of evidence are accumulating about the connection with estrogen, but this needs to be studied further.

Medscape: Lung cancer is a devastating diagnosis.

Dr. Schiller: Yes, it is. An often-quoted fact is that lung cancer kills more than breast, colon, and prostate cancer combined. In the United States, lung cancer is the cause of one third of all cancer deaths; it is the second most common cause of death after heart disease.

In my opinion, patients with lung cancer should not feel guilty and ashamed. In the 1960s, the tobacco companies had huge marketing campaigns; they gave away free cigarettes and even had ads with doctors endorsing different brands. Once people started smoking, most of them could not stop.

Medscape: Why did Genentech support this study?

Dr. Schiller: Drug companies want patients to be empowered so that they will be compliant with their regimens. If patients feel bad about themselves, they will not be proactive and they will not demand the best care. Our ultimate goal is to overcome the stigma so that lung cancer patients will be empowered to seek the best care and not to be satisfied with no care, or only 1 line of treatment, inadequate clinical tests, and lack of clinical trials.

References

1. Schiller JH, Bowden CJ, Mills J, et al. Explicit and implicit attitudes toward lung cancer (LC) relative to breast cancer (BC). Program and abstracts of the 2013 Annual Meeting of the American Society of Clinical Oncology; May 31-June 4, 2013; Chicago, Illinois. Abstract 8017.

Medscape Oncology © 2013 WebMD, LLC

*From **Medscape Oncology** in association with the **UT Southwestern Medical Center***
Cite this article: The Stigma of Lung Cancer. *Medscape*. Jul 18, 2013.